

FULL COUNCIL MEETING MINUTES
April 15, 2019 - 1:00 PM
STATE COUNCIL FOR PERSONS WITH DISABILITIES
Felton-Farmington Room, DelDOT Administration Building, Dover
(CART/ASL Provided)

PRESENT

Todd Webb, Chair/DelDOT-ADA; Terri Hancharick, Vice-Chair; Gene Aucott, Easter Seals; Susan Campbell, DHSS/DMS/Birth to Three; Anthony Carter, JEVS; Karen DiNardo, State Rehabilitation Council; Susannah Eaton-Ryan, The Arc of Delaware; Moni Edgar, CAP-UCP; Rosanne Faust, DSAMH (for Elizabeth Romero); Kristy Handley, BIAD; Rick Kosmalski, Developmental Disabilities Council; Dale Matusевич, DOE; Karen McGloughlin, DHSS/DPH; Daniese McMullin-Powell, Advocate; Jim Miller, Polio/Post-Polio Support Group; Robert Overmiller, GACAPD; Lauren Reynolds, FCIL; Loretta Sarro, DVR-ODHH; Lloyd Schmitz, Council on the Blind; Wendy Strauss, GACEC; Belinda Strickland, DART; Meredith Tavani, DSCYF/PBHB; Leslie Hailey, DDDS; Cara Wilson, CLASI/DLP (for Laura Waterland); Despina Wilson, IRI, Inc.; John McNeal, Staff; Kyle Hodges, Staff; Amber Rivard, Support Staff; and Jo Singles, Support Staff.

GUESTS

Victoria Counihan, DOJ/AG
William Powell
Carol Stevens
Janet Batchelor, Consumer
Tammy Clifton, Brain Injury Committee
Dawn Lentz, Green Party of DE

Interpreters: Caroline Greene/Peg Stewart

CALL TO ORDER

Todd called the meeting to order at 1:07 pm. Introductions were made. He asked everyone to use the microphones once the connection can be made.

ADDITION OR DELETIONS TO THE AGENDA

None

APPROVAL OF MINUTES

Dale made a motion to approve the March 18, 2019 meeting minutes as amended. Lloyd seconded the motion. Loretta clarified that Sprint is not the Video Relay Provider (page 2-first paragraph). Sprint is a telecommunication relay service provider and there are other video relay providers. The motion was carried with no one abstaining or opposing.

BUSINESS

Medicaid Update (Steve Groff/Lisa Zimmerman, DMMA) and the Lifespan Waiver (Marie Nonnenmacher, DDDS)

Steve provided the following updates regarding Medicaid:

- The Medicaid program is working on health care transformation. DHSS Secretary Walker recently held Town Halls. DHSS is pushing for value-based purchasing and better health outcomes. Contracts with MCOs (Managed Care Organizations) have been amended to incorporate performance measures around quality as well as contracting and value-based arrangements with providers. The first year has been completed. Providers will be facing financial penalties if benchmarks are not met. There is a benchmarking effort statewide to look at the cost of health care among all payors and how fast that is increasing relative to the growth and revenue for the State. DMMA was originally directed by the General Assembly to form a task force and create a Report on Children with Medical Complexities and that report has been completed. Due to barely scratching the surface in the allotted period, an ongoing Advisory Committee (including consumers and their families) will continue to address issues around supportive service needs in the community and how to assist families with care coordination. Steve added that this will inform the work in the adult space since children and adults with medical complexities face the same needs. Updates will be provided as this work moves forward.
- Medicaid for Workers with Disabilities Program. Currently, 78 people are enrolled in this program (working and continuing to receive Medicaid benefits).
- CFCO (Community First Choice Options) – This is not actively being worked on due to other competing priorities, especially around substance abuse disorders. The hope is that many of the benefits of CFCO are incorporated into their program because the Demonstration Waiver gives authority to provide many of the services.
- Money Follows the Person (MFP) Program. This program has been discontinued along original lines of funding determination, but all services have been incorporated into the MCO contracts and the waiver has been amended so that services can continue as originally authorized under the Demonstration Program.
- Medicaid Buy-In Study Group – This group looked at a program that would allow people who are over income for Medicaid, but not necessarily with a disability, to pay a premium and enroll in the Medicaid Program. The Buy-In was not a feasible strategy for expanding health care coverage to additional low-income people. The group is actively exploring a 1332 Waiver that is not specific to the Medicaid Program and falls into ACA Provisions in the Health Insurance Marketplace, but would allow the State that would reduce premiums for individuals purchasing off the Marketplace. The State would still be eligible for a federal contribution to offset the cost.
- An Adult Dental Coverage was included in the budget request this year, but was not in the Governor's Recommended Budget. This continues to be a high priority for DMMA. There is legislative interest in pursuing Adult Dental Coverage and they will continue working on this.

Daniese spoke about several federal legislative bills. One bill would fund MFP until September, but Delaware does not qualify for this funding. She spoke about the Disability Integration Act (S 117 or HR 555). She asked Steve if he would consider endorsing and sending a letter to CMS and to the Delaware Congressional Delegates. Steve commented that he would review and consider such, but needs to do some research. He asked that Kyle or Jo send him the legislative references. He will have the policy team do more analysis. Steve will send a copy of the letter to SCPD if he decides to follow through.

Marie spoke about the DDDS Lifespan Waiver. This waiver was amended two years ago to add more services and to allow people living with family to enroll. DDDS is in the process of implementing this. At least one provider is enrolled for all the categories and they are seeking to expand the network. Providers can now enroll in Medicaid to deliver services. They had some challenges due to system requirements, but it is moving forward and going well. The waiver expires on June 30, 2019 and a

renewal application has been submitted to CMS on April 2nd. A new service has been added to the renewal application called Medical Residential Habilitation. This will allow DDDS to pay residential habilitation providers to employ nurses and the providers are responsible for making sure the nurses are there, meeting required standards, and have all of the appropriate licensures. This includes arranging for back-up.

Marie spoke about another major change for those who have elected the Waiver, live in a provider managed residential setting and receive their regular Medicaid benefits (doctor visits, medication, etc.) under a payment arrangement and fee-for-service method. DDDS is responsible for managing all the non-waiver benefits. The non-waiver benefits will be weaved back into the MCOs effective July 1st. This will allow for more flexibility in the delivery of services and payment arrangements. She feels this will result in better health care services for members.

Kyle asked Marie to speak about people who want to receive services from DDDS and they are required to have Medicaid. Marie explained that some individuals were not eligible for Medicaid for home and community-based services and Medicaid because their income and/or resources were higher than the limits. DDDS is now requiring that they enroll in the Waiver to replace what had been State-funded services. Almost everyone who is eligible for DDDS services would be eligible under the Lifespan Waiver. Excess income and resources can be put in protected trusts, for example, the ABLE Account or Miller Trust. She also spoke about the Delaware Care Plan, which is a Pooled Trust and the person would have access to money for their needs. Kyle asked if anyone was going to lose services due to the transition and how many people would be affected. Marie explained that no one should lose services as a result unless they are not a citizen. They have worked first with people who have not received services before and then working with families who have received services. They now have the option of leveraging Medicaid funds, which they did not have before. She added that there are many unmet needs and many competing priorities with vulnerable populations. There is currently a rate increase in the Governor's Recommended Budget for FY 2020 and they would like to augment that increase in 2020 or 2021. They are working with Bank of America on ways to minimize the harm to an individual so they would not have to cash in their 401k and pay a penalty. Kyle said he has been hearing concerns in the community about the rollout. He asked how many people would be affected. Marie stated that they started out with 400 people who were receiving State funded services out of 4,600 (total DDDS population), although children still in school receive services through IDEA/DOE. Kyle asked how families are reacting to having to put money into these trusts. Marie commented that the reactions have been mixed, but she thinks that once they have a one-on-one with the family and discuss their particular needs, they will alleviate concerns. She added that they do not provide advice on which financial trust should be used and they are referring families to an eldercare lawyer or a lawyer who specializes in Pooled Trusts.

Terri asked if Medicaid Buy-In would help with this. Marie stated that some people will be eligible because they are in the Medicaid for Workers Disability Program. Terri asked about people who are on Long Term Care and not going to the Lifespan Waiver. She asked if there is a day program and are they in talks with the MCOs about paying for the day program. Marie stated that they are having discussions with DMMA about how that would look, and how those processes could be streamlined. Terri asked, if the MCOs decide not to cover day care programs, would the person have to make a choice about the Lifespan Waiver to receive day program services. Marie added that these services are covered under the State Plan under the rehab option, but CMS has told most states to close out the rehab option many years ago because the services delivering are habilitative services. This has not closed in Delaware, but she thinks it is a matter of time.

Wendy stated that some parents have met with attorneys and they were unsure of how to advise the families because they were unsure of the expectations. Wendy asked what these families should be telling the attorneys. Marie stated that they are considering a new approach where families would apply for the waiver, getting the denial letter (with over income amounts) and take the letter to the attorneys. Wendy asked if this will happen in a timely way to meet the deadline. Marie explained that they have been working on this about a year ago. For those working toward moving to becoming eligible for the waiver, DDDS is not intending to cut off their State funded services as long as they are actively working toward a solution.

John asked how many receive insurance through Bank of America. Marie stated that about 30 people and this is a small portion of their population. John spoke about his frustration in navigating around the Miller Trust. He stated that it is costly to set up (\$500-1,200) and this is a disincentive. Another frustration is finding someone who is knowledgeable and understands how the Miller Trust works. He added that having insurance through a company while working saves Medicaid thousands of dollars a year. Marie stated that in 1981 the resource allowance for SSI and Medicaid LTC Program was \$2,000. Currently, the income limit is \$2,019. Marie commented that the federal government makes the rules and they try to maximize the funding. John added that this is something that we should be taking this to the feds to address. Todd thanked John for bringing this up.

Kyle asked about funding being used to set up the trusts. Marie commented that people who need the trust have resources to pay for set-up. Kyle asked if regulations are being published for the transition. Marie stated that eligibility regulations will be revised. They are also changing the order the structure of the eligibility regulations and will include language that people must become eligible for Medicaid in order to pay for services that Medicaid cannot pay for. Many clients are not eligible for Medicaid due to being in school and not currently receiving services from DDDS. If they are not eligible, DDDS will pay for these services. This is for people who cannot enroll in the Lifespan waiver. Marie stated that the regulations are actively being worked on and will be published as soon as possible. Kyle thanked Marie for attending today's meeting.

Kyle referenced a letter from CMS (handout) sent to Medicaid Directors regarding Home & Community Based Services and the heightened scrutiny process. Lisa stated that they are working with DDDS to find out what this means for Delaware, but does not have a definitive answer today. Kyle asked about a time frame. Lisa stated that CMS recently provided technical assistance in the form of a webinar that staff participated and that they are in the beginning steps. Kyle asked about notification when a proposal is drafted that it be put out for Public Comment. Lisa commented that information will be shared publicly and put on their website. Daniese commented that she is hearing from Washington, DC is that the Rules did not change, but that some of the examples were removed. Lisa added that some of the examples where a determination was not made about heightened scrutiny was provided to them and that they need to pay attention.

Kyle asked Steve when the provider contracts are due for renewal. Steve stated that the MCO contracts are up for renewal in 2021. Steve stated that AmeriHealth offers a preventive dental benefit. Kyle asked if the 78 people receiving Medicaid for Workers with Disabilities Program are they full-time/part-time or both. Steve will follow-up with this information. Kyle asked for statistics on how many people have transitioned through the MCOs. Lisa will follow-up on this. Kyle asked if CFCO would leverage federal dollars. Steve commented that they had not finalized the analysis. He added that what they have heard from other states is that it drives up costs. Steve commented that it would be good to review the programs

before they went to CFCO vs. what we already offer. Kyle thanked Steve and Lisa for attending today's meeting.

Committee Reports

Employment First Oversight Commission (EFOC)

Kyle stated that we have received most of the baseline data requested from specific agencies. He is waiting for information from DSAMH; DSAAPD and DSCYF. The EFOC is obtaining information on how Employment First is being implemented for the people they serve. He added that we want to work with them if they have not done this.. Lloyd stated that EFOC promotes employment for people with disabilities. He stated that we are lacking membership from people with disabilities. His term has expired. We are looking for people who want to promote employment for persons with disabilities. Kyle will provide a copy of the Code. The membership is a three-year term and meetings are held once a month at Smyrna Rest Stop, from 9:30–11:30 am. Moni indicated an interest in serving. John commented that there is a process since membership is by appointment. Kyle added that they are working on amending the legislation. Terri suggested a potential member, Christopher McLaughlin (DVR), who recently spoke at a UCP Conference. Kyle will follow-up with Moni and Terri.

Lloyd stated that we are currently in talks with DHR as it relates to the Selective Placement Program in the State. Kyle added that we are trying to schedule a meeting with them. Todd spoke about the challenges people in the Project Search Program face. Many entry-level jobs have non-essential requirements that are not essential to the function of the job. He gave several examples and stated that this is a major barrier for this population. It was noted that Dale is a member of EFOC. Lloyd also gave an example and stated that the meeting with DHR is to discuss these issues. He added that EFOC has representation from DVR, DOE, DSAMH, DDDS and veterans' groups. Dale stated that they are focusing on educating employers, not only in hiring individuals with disabilities, but reworking the job descriptions. He added that we will continue to expand work-based learning opportunities for individuals with disabilities. We will continue to look at the customized employment aspect of jobs and working with employers to bring in people. We need to take a step back and look at what are the essential job duties. Todd asked who should we be contacting when we find barriers. Kyle stated that Todd was welcome to attend the meeting with DHR. John commented that this can be asked at the meeting with DHR and encouraged Todd to attend. Lloyd added that Jane Hahn oversees the Selective Placement Program and oversees the website for job postings. Keith Hunt is her supervisor and he is the Director of Diversity. Todd wanted to know what resources are available for individuals with disabilities who are employed to know what their legal rights are for requesting special accommodations especially when it comes to training and education. Todd will email this to Kyle. Kyle will let Todd know when the meeting with DHR is scheduled.

Brain Injury Committee (BIC)

Tammy Clifton introduced herself as the new Chair of the BIC. She is also a board member of BIAD (Brain Injury Association of Delaware) and works for the Division of Vocational Rehabilitation. Formal by-laws were recently adopted. They are on the SCPD website: <https://scpd.delaware.gov/pdfs/BIC-Bylaws.pdf>. A Prevention & Outreach Subcommittee formed with two representatives from each county. Their goal is educational outreach out to rehab facilities, physicians, medical practices, medical providers, and hospitals. The Data Subcommittee met with Randy Farmer, Chief Operating Officer of the Delaware Health Information Network (DHIN) to discuss obtaining data on the number of people who have

incurred a brain injury. One of the barriers is there is not a mandate for hospitals or health care providers to report brain injuries. Another barrier is that depending on their priority diagnosis and the brain injury could be listed further down in the record and less identifiable. Tammy stated that a survivor input component was added to the BIC Agenda as a standing agenda item. A brain injury survivor attended and shared her story and provided some of the challenges she has faced.

Tammy then spoke about the Brain Injury Fund. Nine (9) applications have been received since January. Three applications were approved and four are awaiting additional documentation. Two applications were denied. Information on the Brain Injury Fund has been shared with multiple groups.

The Vice-Chair of BIC and President of the BIAD recently met with Congresswoman Lisa Blunt-Rochester's Project Director to gain her support of National Brain Injury legislation and the need for a Brain Injury Registry in Delaware. We are looking for a greater voice from our legislators. Kristy Handley, Sharon Lyons and other Board members are meeting with Senator Carper this Friday. A review of the Priorities, Goals & Objectives from 2017 has been initiated. There will be a retreat after July 1st.

Karen stated that she is the Chair of the Data Subcommittee. She added that this subcommittee met with DHIN and were pleasantly surprised that they had great information to share and the barrier around collecting data for brain injury may not be as insurmountable as originally thought. In addition, the financial cost in putting this together may not be as much as anticipated. We are now talking about \$1,000-5,000. We originally thought the cost would be \$100,000. This is very positive and hope to have more information soon. Karen asked people to reach out to her if they wanted to see more from this data collection or ensure that the correct data is being collected.

Kristy spoke about the receptiveness from Representative Rochester's staff during the meeting. They discussed the lack of coordination of services when people are leaving the hospital. They also discussed the needs for a Brain Injury Registry in Delaware. Her staff will be following up with actions that need to be in place, enforcement of data collection, and education in the school regarding concussion protocol. Karen added that DHIN stated that all hospitals are reporting and no matter how far down the list a brain injury is listed, the information can be pulled out. It still needs to be written on the record. Kristy stated that there is no one from Delaware represented on the Brain Injury Task Force (federal). This issue will be brought to the attention of Senator Carper and Representative Rochester.

John stated that there is \$70,000 left in this year's budget for the Traumatic Brain Injury Fund. Of that amount, \$50,000 can be carried over into the next fiscal year. He would like to see this money used. Some legislative changes may need to occur. John spoke about the legislation passed in 2016 and went into effect in 2017 relating to concussion protocol in non-scholastic athletics in Delaware. Increasing public awareness needs to happen. The DIAA (Delaware Interscholastic Athletic Association) has a data base that shows who completed the training every two years. The legislation references impact sports, but is not clear. September is National TBI Month. John is working with Kyle on how to get concussion protocol followed in a consistent way. Kristy spoke about her personnel experience with her children playing sports. Karen commented that the Prevention & Outreach Subcommittee wants to increase awareness about this concussions, etc.

Karen spoke about a Concussion Conference she recently attended. She commented about the power of having people who have had concussions speak about their experiences. Todd spoke about the high rate of head injury from motorized sports, BMX racing, and harness horse racing, etc. and defining the term contact sports. John spoke about closing the gap and the need to cover all sports and there may be a better

way through regulations to work that out. The language is in the regulation for collaboration and is overdue. John spoke highly of Dee Rivard's work with the Brain Injury Committee.

Policy & Law Committee

Kyle referenced draft legislation (handout) regarding preventative and urgent dental care for adult Medicaid recipients. John, Todd, Terri and he met with Senator Townsend. DMMA is on board with this. Kyle referenced comments submitted by the DLP (handout). We commented about the amount of the co-pay being too high and that multiple conditions for emergency services, when one is enough. Kyle hopes that this legislation will be introduced this year. Karen suggested speaking to the Dental Director at DPH.

Kyle spoke about SB 28, which has passed the Senate. SCPD sent comments supporting the legislation, but added that there is a lack of accessible space and enforcement needs to happen. He referenced a chart showing the number of tickets given by various police departments throughout the state.

Housing Committee

Kyle and Daniese attended a meeting on Impediment to Housing. They will attend future meetings. Daniese spoke about the 811 Project and the 140 slots. The vouchers stay with the project. Only 30 people have been included out of 140. Someone has to move out before the place is designated for persons with disabilities. In Delaware 20 percent of the project can be designated for persons with disabilities. Services are not connected to the unit but must be available. Lloyd asked what needs to happen to activate the Housing Committee. Daniese stated that we need people who are interested in serving on this Committee. Lloyd asked how you find people and this needs to be taken to the next level. Daniese asked if anyone attending was interested by show of hands. Lloyd commented that there is a need and we need to get people involved. Kyle will review the existing list and reach out. He said we need a plan and agenda items. Daniese, Terri, Todd & John will be discussing this.

Kyle spoke about the legislation regarding participation by phone in meetings. Kyle, Laura, Terri and Daniese are working on a draft legislation. He hopes to have something finalized soon. Wendy asked if there was information on the Planning Committee. John commented that he would have discussions and move forward in the next fiscal year.

ANNOUNCEMENTS

John asked everyone to respond to Jo's email regarding attendance. He said that we need to ensure that we have quorum to do business. He said that there is quite a cost to have interpreters and CART services at each meeting.

Karen spoke about April being Sexual Assault Awareness Month. There is an event called Denim Day on April 24, which included about a mile and a half walk near legislative mall. She encourage people to participate and support this event.

PUBLIC COMMENT

None

ADJOURNMENT

Todd thanked everyone for attending and participating. He encouraged new people to attend future meetings. The meeting adjourned at 3:13 pm.

Respectfully submitted,

Jo Singles
Administrative Specialist

SCPD/minapril19